

TESTIMONY BEFORE THE DEPARTMENT OF PUBLIC HEALTH
REGARDING H.B. No. 5499,
PROPOSED HOSPICE FACILITY REGULATIONS
March 13, 2012

To Department of Public Health., my name is *Carol Emmerthal, RN, MSN*. I am the Director of Hospice and Palliative Care of Northeastern Connecticut, a program of Day Kimball HomeCare. This letter is being sent as **written testimony** in support of H.B. No. 5499. The regulations are based on the Medicare Hospice Conditions of Participation and provide opportunities for **all** licensed hospice providers in the state to be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence must be able to provide the following levels of hospice care: routine, general inpatient, continuous or respite.

My testimony advocates for equal access to the full realm of hospice services for all residents across Connecticut.

During my 20 plus years with hospice, I have developed a deep appreciation for the care provided by hospice providers throughout Connecticut, be they not-for-profit or for profit agencies. We all focus on the special end of life care needed for our patients and their families. We are all united in our missions and philosophies to provide quality care to the terminally ill patients we serve. We advocate for the needs and safety of our patients and families including where they wish to live the last days of their lives.

This leads to discussion regarding the area that I have seen significant **inequities**; that of access to hospice facilities. Presently, Connecticut Hospice is able to provide a full spectrum of inpatient and outpatient care in the Branford area. The new regulations expand the ability for all hospice programs in Connecticut to provide this care in their communities without altering the structure that is established at Connecticut Hospice. Personally, my father in law died at the Branford facility. I will be forever grateful for the care that he received and the support that being able to place him in that facility gave our family. They predominantly lived in close proximity to Branford so access was close and easily negotiated.

That being said, the same access is not available in eastern and northeastern Connecticut. In my experience, access to this type of care is nearly impossible for our residents. Branford is 2 hours away

and driving that distance on unfamiliar roadways is not reasonable or safe. Families and friends who would like to visit are torn. The four hour round trip severely impacts their ability to work and to provide the care needed to maintain their families. They are forced to make difficult choices that include limited visits to their loved ones who are dying a distance away. For our terminally ill patients, having to be transferred out of our community further isolates them from the ones that are most important to them. This is a time when making these last memories with family and friends are essential to the patient's comfort and to the family and friends ability to cope through the illness and into bereavement. Family and friends of those dying should not have to make these difficult choices. They are already stressed.... Significantly stressed with their anticipated loss of a loved one.... But to lose the ability to spend time and to make forever memories should not be part of the equation. Transfer to Connecticut Hospice in Branford is not a compassionate option for our patients and families.

Our program has had to transfer patients from northeast Connecticut to hospice facilities in Massachusetts and Rhode Island. These facilities having inpatient levels of care with the specialized hospice focus were closer to our patient's homes. The closest facilities still require families to have to negotiate urban roadways and highways. Although closer, they are out of state and remain a distance from our community. This transfer also poses issues with some insurance carriers who may not have agreements with out of state organizations. Out of state transfer is not an option for our patients who have Connecticut Medicaid.

From a personal standpoint, were my mom to require hospice inpatient level of care, I could not consider sending her to Branford for this care. This transfer would mean that she would lose access to many of her senior citizen friends. Family members.... her sister, grandkids, her nieces and nephews would only be able to visit sporadically. At a time when she should be surrounded by love, she would find herself isolated and alone. Her true access to this level of care would not be possible in eastern Connecticut and our family would not have the choice as we did with my father in law. Is that fair when your life is truly limited and families are already stressed by their anticipated loss?

Another option is to provide this level of care in area nursing homes. We presently have contracts with area nursing homes to provide care. This is the option that is often chosen by our patients, not because that is truly where they choose to go but because those nursing homes are in our community and they, at the very least, will be able to have family and friends close. Although an option, it is not optimal for some at end of life. I will give an example of one person who was cared for by our program. This was a

younger woman. She was unable to stay at home due to lack of a caregiver 24 hours a day. Her husband had to work to maintain the family. In order to see her family on a daily basis, they made this decision. It was difficult for her, her family and even for our staff. The nursing home did an excellent job with her care. That was not the issue. The issue was that she was in a facility more designed for our elderly geriatric populations with chronic illnesses. There were limited facilities for overnight stays for the family or private homelike spaces for family to gather. Many nursing homes will not allow IV or subcutaneous means of administering symptom medications. A hospice facility, located in the local community would have provided the total package of hospice care.... the physical, emotional, social and spiritual care that is critical at end of life. She deserved this... her family deserved this. Our community deserves this option.

I personally don't believe that there will be hospice facilities popping up in all communities, however I do feel that this is a time for hospice organizations regionally to work together to establish hospice facilities with multi care levels that are much closer to where patients live, to their home communities and to their families. It is not about competition but about good quality care. These regulations would support greater access to excellent quality hospice care in Connecticut.

Speaking as a hospice professional and resident of eastern Connecticut and representing the issues of our communities, I strongly support H.B. No. 5499. I strongly urge you to support the proposed changes and become a champion for quality of end-of-life care to clients and their families throughout the state. The proposed regulations are not only about convenience, it is about opportunity and patient choice at the end of their life. The regulations are about the delivery of comprehensive hospice services that includes hospice facilities throughout our state.

Thank you for taking the time to consider my written testimony. Please feel free to contact me if you have questions.

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